Introduction and guest background

This is Doctor Talks, real talk from real doctors on the issues that matter to you most. Hello, everyone. My name is Dr. Richard Horowitz, and I am the co-host of the Healing Lime Summit 2.0 with Doctor Talks.

And it's my great pleasure today to introduce to you Jennifer Crystal. So I met Jennifer several years ago when we were working on the Harvard Lyme Wellness Initiative.

Jen and I worked for Harvard on this tick-borne disease group. And that's how I met Jen for the first time. And Jen has a memoir that just came out. It's called One Tick Stopped the Clock.

So obviously, very clever with the tick-tock. So Jen, it's a pleasure to have you today. We're going to discuss your journey through healing from Lyme disease.

what you went through, how many doctors you saw, the disbelief that your friends and family and other physicians had. And I think lessons learned navigating this chronic illness path, I think it's important for everybody.

So tell people a little bit about you, what happened, how you got sick, the path of life you were on before this whole thing happened, just so people can get a sense of where you were and how deep that hole was that you went in before you managed to pull out.

Sure, and thank you so much for having me, Dr Horowitz. It's great to be on here and get to talk to you about the book and about my experience. So I was bitten by a tick in the summer of 1997 while working at a summer camp in Maine, but didn't realize at the time that that is what had happened.

I had a red rash on my arm. It was not your typical bullseye rash. It was a splotchy red rash, and I didn't learn until many years later that EM rashes can present in many different ways and that many people don't even find or get a rash.

But because it wasn't a bullseye rash, the camp nurse and I just sort of brushed it off. Lyme disease was not on my radar at the time, even though I was from Connecticut, even though I was working in the woods of Maine.

The camp nurse was from England that summer. It was not on her radar. And we sort of thought, I don't know, maybe it's from my sleeping bag or something.

It doesn't itch. It doesn't hurt. Don't worry about it. And the rash faded and I never gave it another thought. Well, that summer I also developed hypoglycemia, which seemed to kind of strange that that just seemingly came out of nowhere when I was otherwise taking good care of my body.

And no one really kind of got to the answer or put together whether that may have been related to the rash. And then that fall, I was a sophomore in college and I had a terrible flu.

They thought I had mono, which is what they always test for in college. And when I didn't have mono, they said, you must just be run down. You must be stressed.

Maybe it's all in your head. I had fevers. I had joint aches. I had exhaustion and difficulty getting to class, difficulty walking to the dining hall.

And those symptoms waxed and waned for years. I would, you know, get better and was leading this really high achieving, high functioning life, double majoring in college and skiing and running and studying abroad, but I would crash.

I would have, you know, I would go have this, this on and off again flu that would come on.

Early Lyme symptoms and misdiagnosis

Um, and the college health center nurse is tired of me eventually. And, you know, said, maybe, maybe you should see someone in counseling about all of this.

And I started to think maybe it is all in my head, even though I had fever, even though I had, you know, but, you know, I just started. By the way, it's difficult to make up fevers.

Right. That's kind of a tough one, aches and pains, okay, you know, whatever, but fevers, that's really a tough one, yes. Yeah, exactly. Exactly. So my blood work all looked fine.

I didn't have mono. They didn't know what else to say. And at that time, particularly, there was more stigma around mental health that, to me, to have someone say maybe you should see someone in counseling really felt like code for it's all in your head.

You're making this up. And it probably would have helped to see someone in counseling because of the angst and the anxiety I was feeling from being so sick all the time.

That probably would have helped. You know, I have a joke I tell my patients because your story of the patient coming in and saying, it's all in my head.

I actually validate them. This is the joke I use and say, well, they were right. It is all in your head. You had Lime Spirochetes in your head. You had Bartonella in your brain.

You had mole toxins in your head. It's like, it's not what they meant. But in a sense, it was right. Now, this was what year? You got sick in what year, roughly?

1997. So already this had already been out for a while with Lyme. I mean, Lyme was discovered at that point in the 1970s. I mean, I was already discovering, you know, Babesia and a lot of the tick-borne diseases in the 1990s.

So, boy, it's a shame because it was already a known disease, but I guess really not well enough known at that point in time. Not well enough known at that point in time.

And if only I had known you then, then my whole life might have been different. But I just, you know, it wasn't on my radar, wasn't on the radar of any of the doctors I went to, and it wasn't until 2003. So after I graduated from college, I moved out west to Colorado.

I'd always wanted to be a ski instructor. That had been my life dream to do that for a year. And I had moved out to Colorado to do that. I hadn't been able to do it right away because I had torn my ACL in my knee.

So I was a school teacher rehabbing my knee, which turned out to take much longer than expected because there were spirochetes in my knee, but we didn't know that.

And so I had finished two years of teaching. I was just on the cusp of, okay, now I'm really going to do it. I'm going to be a ski instructor for a year.

and for the summer I was heading back to the summer camp where I had the initial tick bite. I was driving cross-country and got so sick and it turned out, ironically, I actually did have mono.

After all those years of being tested for mono, I finally actually did get mono in 2003 and my body could not fight it off because it had underlying tick-borne infections of Lyme disease, babesiosis or lichiosis, which we later discovered.

And so, by the way, many people that I see have immune deficiency when they have chronic Lyme disease. So it's not unusual at all to get these viral infections that keep coming back.

A large percentage of my patients have EBV. In fact, with COVID now, it's become even more frequent to get these EBV reactivations and herpesvirus 6 reactivations.

You know, it's never usually one thing. right in my world when people are sick. My model is the 16-point MSIDS model. And it's like going into a doctor with 16 nails in their foot saying you have pain.

The doctor fires one nail. So with the model, of course, there's no great treatment. So at that point, when you were having these flu-like symptoms, were these monthly, was it around your period?

Because many women around their menstrual cycle, right before, during, or after, that's when the symptoms come out. Was it that for you, or was it like on and off throughout the month when you had it?

It was kind of on and off throughout the month. Later, once I actually was finally diagnosed with tick-borne illness and was undergoing treatment, I did notice that my symptoms were much worse around the time of my cycle.

Right during my period, I was getting these excruciating migraine headaches and just all of my Lyme symptoms seemed much stronger at that time. Thankfully now that's no longer the case, but I definitely noticed that once I had been diagnosed.

So now to 2003, it's at least six years at this point that you're still sick. They called it mono, which, of course, there's no great treatments for. There's a few new ones, by the way, that have come out, but we're trying them.

So how many doctors do you end up keep seeing at this point with these symptoms? And tell us, was it brain fog, memory concentration, fatigue? Was it migratory pain, which is the hallmark of this disease?

Absolutely. Yes. I had pain in various points of my body, often had migraine headaches on one side, on the left side. the you know flu-like fatigue was excruciating you know not just a little bit tired but I'm bedridden I can't you know I cannot get out of bed and again I'm a person who's a skier who's you know a teacher who's like always burning the candle at both ends highly active and you know so for me to to say I can't get out of bed is really like I'm completely exhausted completely spent completely wiped out So how many doctors did it take?

I mean, roughly along the, and I understand you were gaslit because in reading your book, you were definitely gaslit by some of these doctors. Tell us some of the stories of like what you told these doctors and what they were actually telling you was wrong with you.

Yeah. So there were more doctors than I could count, but dozens of doctors, I would say. The mono was easy to diagnose because that was a blood test. And so then, okay, you have mono and now it's slipped into chronic active Epstein-Barr virus.

So I'm not sure what number doctor we were on at that point, but it was many doctors before then, and then many doctors after that trying to say, is it still just EBV, trying to figure out what else was going on.

But yes, I describe one experience in the book, a couple different experiences in the book. One was a primary care physician who had diagnosed the mono and the Epstein-Barr virus and had originally told me when I went to see him, it's very unlikely someone your age would have Epstein-Barr.

I don't think that's what's going on. We're going to test for other things and we'll get to the bottom of this. And then he tested for other things. Nothing showed up and he said, you have Epsom bar virus.

I said, but you had said when I came in, that's unusual for someone my age. He said, well, yes, it is, but that's what you have and there's nothing I can tell you to do but rest.

I describe in the book, I was like, is there anything else I can do? How about diet? How about supplements? His response with diet was, well, eat things low to the ground.

Finding the Lyme diagnosis

I said, what do you mean by low to the ground? Well, turkeys, chickens, plants, they're closer to the ground, they're better for you. So that was kind of that was the answer, you know, in a healthier diet.

OK. And then he suggested I see a psychiatrist. And this only acknowledgement the psychiatrist made of my physical illness was to ask if I had a living will.

Then, yep. Oh my God. So not only did they not discover what was wrong with you, but actually putting in your head this could even be a life-threatening problem that no one's figured out, so you better get your affairs in order?

That was the message sent. Wow. And then she totally switched gears and suggested that I buy a social anxiety workbook. And I looked through this workbook and I thought, I do not have social anxiety.

I have always had a very easy time making friends, love going out and doing things anywhere I've been. I'm just too sick to do so right now. And she got very upset with me and said, this workbook is very helpful to all of my patients.

And I realized then, well, what category have I been put into here, you know, by the primary care who recommended me, you know, by the psychiatrist? And what does that say for people with legitimate mental illness, who, you know, for other people, they're being sort of used as a catch-all?

Well, so, you know, other people with a physical illness that we can't figure out, it must be, you know, a social anxiety disorder. Well, and the part that's kind of sad here is both Lyme and Bartonella cause tremendous mental health problems.

In the ICD 10 or 11 diagnostic manual, every psychiatric illness, depression, anxiety, OCD, we've had patients who are psychotic, who are schizophrenic, who come in on schizophrenic medicines, who have Bartonella rashes.

And the psychiatrist never bothered to do a full physical exam and examine to say, hey, What are those unusual rashes? This is, unfortunately, where the medical system is not fully taking a history and understanding what Bob Berenfield will say, mental health, the microbes in mental health, that microbes cause mental illness.

So by the way, to environmental toxins and many things. So did any of these people really do a full physical exam and really go through everything? Because you had a multi-systemic illness.

It was fevers on top of it, as you said, which you can't make up. migratory pain is the hallmark. Did you also have neuropathy, tingling, numbness, burning, stabbing?

I did. I had all of that in my extremities, particularly the burning sensation came on after I was diagnosed with mono and I would be lying in bed at night and my feet would feel like they were on fire.

And, you know, people would say to me, oh, like your comforter is too hot. No, it's not an external thing. It's an internal, like I literally feel like my feet are on fire and I have to take, you know, cold, wet towels to, you know, to put on my legs.

And did this migrate? Because migratory neuropathy is the hallmark of chronic Lyme disease. It did. It would be in my feet. It would be in my legs. It would be in my arms, all over my appendages.

This is why I've recommended to doctors and for the patients out there who are listening. The HMQ, the Horowitz-Emsitz questionnaire that was based on Dr.

Borscano's work years ago, I published this back, I think it was 2017, with researchers from the State University of

New Paltz. And it's a pre-test probability where you just take this questionnaire of 38 items, and there are several other sections, and you get a score.

And if you're over 63, it's two standard deviations above the mean. You have a very high probability of having chronic Lyme disease. If it's questions 1 and 22, day sweats, night sweats, chills, flushing, air hunger, can't catch my breath cough, those are symptoms of babesia.

Now, did you also have some of those symptoms? I did, yes. I had air hunger, particularly, was a big one for me. The hypoglycemia, I guess, was eventually linked to that.

I had night sweats, pouring night sweats, where I would have to get up in the middle of the night and change my pajamas, change my sheets a couple times a night.

And you told this to the doctors, even with the drenching night sweats? Yes, and they never, everything was just sort of looked at separately, first of all, you know, never all put together.

things like that were just considered sort of idiopathic. Like, huh, that's interesting. I don't know why. And it's funny you mentioned that idiopathic because that's, of course, the term in medicine.

It's kind of a joke among the medical profession that idiopathic usually refers to the doctor being a pathetic idiot because they didn't. I'm sorry for any out there who actually are good diagnosticians.

But, you know, in the HMO models and I don't know how many HMO doctors you saw, you're allowed to take, you know, maximum 15 minutes. Did any of these doctors actually even spend a fair amount of time with you or You came in with this prior diagnosis and it kind of even gaslit them.

They thought, you know, you had something so they didn't even bother to look further to see what was going on. Right. And that's exactly what would happen.

One person read to me from a dusty medical textbook about mono and about Epstein-Barr virus. But no, no one had the time or the bandwidth or the interest or whether it was because of insurance allotted time, probably, to really take a complete exam and to look at things like risk factors for tick-borne illness, to look at my complete medical history.

To look at my lifestyle history, you know, just to really look at a head to toe. Nobody had the time to do that. The first time that that happened was I went to see a naturopathic physician after I'd been dealing with the Epstein-Barr virus for a couple of years and wasn't getting any better.

And though he wasn't ultimately able to figure out the answer, he at least did a very thorough exam, was very thorough with me, and validated me and said, we haven't yet figured out what's going on.

But that doesn't mean that something isn't going on. It means that we haven't gotten there yet. Right. So a doctor that actually understood that because I couldn't figure it out, it's not in your head.

Right. Exactly. Exactly. So, well, that's good. At least you had one doctor along the way. But this is, again, many years later. So how many years were you suffering with all of these symptoms until you actually finally got a real diagnosis?

Eight years, yeah, I was diagnosed with tick-borne illness in 2005. And the reason that came to be, I was drying my hair one day, which is notable because I had such fatigue and such pain that doing something like that was difficult for me.

But I was drying my hair one day, maybe I was cold, maybe I was having lunch with someone, I don't know. And my elbows were up like this, you know, from drying the hair so I could see my elbows in the mirror.

And on each elbow was a bullseye rash. And you're one of these people. And by the way, I would tell for people listening, this does not happen all that often, but it does happen.

I've seen over 13,000 chronically aligned patients in my career, but there have been handfuls of cases of people told me that there was almost like the symptoms came back from time to time, including the rash.

You don't really see that much in the literature, but I have heard that from patients. And it wasn't on, by the way, one part of your body. You had it on two different parts.

two different parts. And at that point, I had started getting used to writing symptoms off and thinking that, you know, so I actually went to the naturopathic physician and I said, I don't know, maybe I was just leaning on my elbows funny.

And because I was so used to people doing that to me. And he said, no, he said, you know, I have been suspecting an underlying infection of some kind because you're not getting better from the Epstein-Biovirus and those look like Lyme rashes and you should go see a Lyme specialist.

So that was finally, the clue was finally those rashes that came out in a naturopathic physician diagnosing you. Exactly. At least leading you on. Sending me to the Lyme doctor.

Yeah, exactly. Now, regarding the testing, and obviously if you went to the right Lyme doctor from the beginning, and I know you did see you finally a Lyme literate physician, did anyone along the way just do an ELISA and not do a Western blot?

Did they think of Lyme but just do the ELISA and say, the ELISA is negative, you don't have Lyme disease? That's exactly what happened. So that wasn't until six years in maybe.

So I don't even know if I was ever tested for Lyme early on.

Treatment, herxing, and relapse

Not that I remember ever being told that we're even considering Lyme disease or being tested for it. Six years in, my mom ran into a high school friend of mine's mother, who it turns out had Lyme disease, and was telling her my whole story.

And my mom called me up and said, this sounds really similar to you. Maybe you should get tested for Lyme disease. And neither of us yet knew the complications of Lyme disease testing.

We thought you just go in and get a test and whatever the results say. Now I know, of course, that's not at all the case. But I did. So I had an ELISA test done.

It was negative. And I thought, oh, all right. I had this hope for a minute of maybe I have Lyme disease. And then I got the result of that and said, okay, I guess I don't.

And it was the naturopathic physician who later said to me, no, Lyme disease testing is really faulty and explained to me why that would come up negative, the two-tiered cyst.

I didn't know any of that. The game that I play with my patients, just, again, educating people listening to this, is I love igenex in California because they do an immunoblot with recombinant DNA, so there's no false positives.

But I never just run it, Eliza. But when I was running Western blots through the local labs, like Quest, LabCorp, BioReference, there's a game I used to play with patients called Lime Bingo.

And I would tell them, if any one of these bands shows up, these numbers on a Western blot, Bingo, you've been exposed to Lyme disease or at least a Borrelia species like Lyme.

It's the 23 out of surface protein C, 31 out of surface protein A, 34 out of surface protein B, 39, and the 83 slash 93. And along the way, so if someone comes in and says, I'm having good and dead days, and I'm having this migratory joint pain, and I'm having migratory neuropathy, and brain fog as a young woman, and I'm extremely tired, and they score high in the questionnaire with even one band, that tells me automatically if they've been exposed to a bruleous species.

The problem with the western blots is they only check for one strain of lime. And there's multiple strains at this point. You know, the, the IGINX checks for at least eight and you can have false positives with the 31 band on a local Western blot because of Epstein-Barr, by the way, or autoimmune disease.

But unfortunately, you know, this, this two tiered theory that got out there, it's really only for health departments. to screen epidemiologically large populations of patients.

The CDC, even on their website, they say, this is not meant for an individual diagnosis. And I know this because I worked on the first round of the HHS tick-borne disease working group.

So it's really a shame because the way medical information is being disseminated. You go to med school or whatever naturopathic school, and I think the naturopaths are great, by the way, because I think I practice probably closer to a naturopath when I've learned what they do.

But unfortunately, after you get out, the training in an epidemic like this, because it's insufficient. They give you a yearly training for narcotics, for end of life things, for sexual abuse.

But they don't give you training for things like Lyme disease, which is an epidemic proportion. And that's really a place in the health care system where we really need to make some changes.

So yeah, your story is really classic in that way. So again, so now we'll get 2005, 2006. The naturopath is putting you on. So after that, how many doctors did you finally see before you actually got the diagnosis?

Thankfully, just one, because the person who my mother had run into, that person with Lyme disease, recommended me to her doctor. So I went to him. I was tested by Igenix.

I had a CDC positive test for what it's worth. By the way, do you remember with the CDC test if it was IgM or IgG positive? I think it was both. Okay.

The reason that I say this is because in a lot of Lyme patients, when Borrelia burgdorferi, the agent of Lyme gets into your lymph nodes in a lot of patients that wipes out the B cells.

So you only make IgM antibodies and you don't make IgG. So these people come in with CDC positive IgM, immunoblots, Western blots, and the doctors will sometimes say it's a false positive because you've been sick for so long and IgM is only early.

disease, but in Lyme, it's early and it's late because of what happens immunologically to the body. So yours was both. You actually had a really. My recollection is it was both.

I do remember seeing on the blood work. It's, you know, written. It said CDC positive with a big circle around it. Like, no, no question. Babesia, because you were having those nights with the Babesia test came back.

And Ehrlichia as well. Okay, and the Babesia test, was it eigenics, was it a fish, was it active Babesia, or is a Babesia microti, duncani, do you remember at the time, like what strain?

I don't remember at the time, yeah. Because again, a lot of patients, the doctors are smart enough to say, oh, you're a young woman. You've got night sweats.

They do a differential diagnosis like you're not in menopause. You don't have hyperthyroidism. You didn't go to

India for malaria. You don't have tuberculosis or non-Hodgkin's lymphoma.

In other words, they do a real differential. And then they realize like, OK, it's babesia. But if they don't check for all the strains, because there's Babesia microti and Babesia duncani, others that are now in the US like MO1K1, they will also miss it.

So the advantage of the eugenics test with the FISH test, it'll tell you, even in people that are immunodeficient, you can see it under the microscope.

And T-LABS also does a very good job with this, including a new species called Babesia otocolli, which comes from Canada. So we're starting to see these species in our practice.

So when you finally saw your lime litter at doctor, Did you do a separate Babesia treatment apart from the Lyme treatment? Yes. Yes, I did. I did anti antimalarial medication.

And this is the thing that I'm always saying to patients or, you know, people when I'm trying to spread awareness about tick-borne illness is that other tick-borne illnesses require different treatment, particularly Babesia.

And so I'm always saying to people, if you only think you have Lyme disease and you're only treating the Lyme disease and you actually also have Babesia, then you're only fighting half the battle.

So so, yes, I was on antimalarial medication. And the babesia wouldn't have gotten better without that. Right. Now, when you did this, you did this treatment with the anti-malarials back in like the late 2000s, though, at the time when this happened.

Exactly. Now, at the time, mepron azithromax, a tovacoin azithromycin, was the classic treatment. And it did work. My first case in Dutchess County, I had a woman in a wheelchair for five years who couldn't walk with chronic Lyme with drenching sweats.

I did the differential, we sent out the ticks from Dutchess County, we sent out her blood, positive, and she ended up walking months later from mepron azithromax.

Now, fast forward, you know, almost 20 years later, the mepron azithromax is not working so well because the parasites have become resistant. I mean, it's become me a nightmare, honestly, for some of the clinicians out there, because even though there are some newer treatments, like it's a phenoquine and a TovaQuone, I don't find it works for every patient who comes to see me.

And it may be because it's these new strains of Babesia otocoli, but thank God for you, it did manage to make you better, because Babesia makes all your symptoms three times worse.

And it's the one I've struggled with the most as I, you know, as my journey has gone on, it's been the Babesia symptoms relapsing more than other symptoms.

That too has gotten better and better and better, knock on wood, you know, so it used to be that I would have to be retreated for Babesia every six months or so.

Now I haven't been treated for babesia in at least five years and and I'm feeling great, knock on wood. So with all this trauma that you went through, I mean, one of the hallmarks of your book is the resilience that people have to get.

Right. And speaking up. Right. Not not just accepting like you. Unfortunately, in this day and age with these diseases, you actually have to in fact be your own advocate.

Tell us a little bit about that journey. Do you think you had resilience as a kid and it was just something you came with or something you developed? And because it's really important when you're dealing with these chronic

illnesses to have resilience and to get to the place where you are now.

You think it was something innate in you, something you developed over time? How did you develop it? What do you think was responsible for it? That's a great question.

And I think it's a little bit of a combination for me. I think I learned resilience as a child. Ironically, as a camper at the summer camp where I got the tick bite when I was 19, that was a summer camp that I went to every summer for seven weeks.

And we just, you know, you had to really work through things, work through different honors and challenges and the skills that we were learning. And part of what we were learning at that camp was resilience.

And so I feel like the place where I happened to get sick is also the place that gave me the skills to survive that illness. That's fascinating, actually.

Yeah. But also, I think it was my friends also who were my stalwart supporters. Even when we didn't yet know what was wrong, they believed in me, stood by my side, believed that things would get better.

kept the faith for me even when I had lost it completely. And I think that that really helped me to be resilient and to not give up even at times when I wanted to or I was ready to.

So I think it was sort of a combination of those things. And probably also just always sort of being a go-getter and a people pleaser and wanting to do well in school and at my job.

And so I wanted to do well in healing from Lyme disease. Right, because you don't make it onto the Harvard Lyme Wellness Initiative without being a go-getter.

That just doesn't happen by accident, right, at that point in time. So no, it's great. You're kind of giving back to the community and let them know your story with it.

So your friends were really, I mean, everyone needs a good support system, obviously. And by the way, many of these support systems, people get burnt out.

I mean, I've had patients divorce. where the husband's, the wife was sick for many years and the husband couldn't take it. He just didn't have it in them.

And I don't think we're trained in this society. You get married and it's for better, for worse. I don't really think we are taught the tools that we need in marriage.

My wife and I are about to do a standup comedy soon about our marriage and things that I've decided in my medical career, it's time to branch out a little bit.

We're actually talking about our marriage and after 20 years, But I will tell you, even resilience in marriage of like the tools you need to get along with someone and to make it work.

I wish they would teach these things in school because they don't teach parenting skills. Could be an important tool considering about 97% of the kids that come in have dysfunctional parents.

I see three out of 100 come in with loving, warm parents. I look at them, I go, hold on, I just want to examine you for a while and take this in because I barely ever see it.

Your family, it sounds like they were supportive, but did they believe you in the beginning or they were not really on board and couldn't understand who you were and what was happening to you?

How did your family react to this and how did you react to them? They were skeptical in the beginning and they

were scared, you know, which I understand like, you know, when I look back now from a point of reflection, I can see how hard it is for caregivers, how hard it is for families when, you know, someone in the family is suddenly sick and they're not supposed to be, it's not at a time, it's a time in their life, they're supposed to be out on their own, they're in their, you know, young 20s, supposed to be, and then suddenly they're sick and they're back under your roof.

Resilience, family support, and advocacy

And so I can look back now and see like, that was really hard for them because, you know, they didn't know what we were dealing with. Um, but yeah, they, you know, definitely had the, had the skepticism in the beginning.

And then even once I was diagnosed with Lyme disease, there really was a, and other tick-borne illnesses, you know, with tick-borne illness, there was still not really an understanding of, you know, what those illnesses were.

I was mostly going to doctor's appointments on my own, you know, it's that's changed a ton. Now, my stepmom will come with me and, you know, ask questions and take notes and is very lime literate.

But there was a definite learning curve for all of us. And actually, I write about in the book, you helped change it for them, Dr. Horowitz, because they went to there was a Lime Conference in Connecticut one day with several speakers, including you.

And I said to them, to my dad and stepmom, you know, I'm too sick to go, but I would really, you know, Love it if you might be able to attend this conference.

And they came back from the conference and they had heard you say that you could see 1000 patients and have 1000 different protocols and that every case is different.

And they came flying through into the house and said, you really have Lyme disease. Yes. So directly by speaking at that conference held, by the way, those Connecticut conferences, I know which ones you're talking about.

Senator Richard Blumenthal was governor of Connecticut at the time. It used to be a joke that every time I was in Connecticut speaking at a conference, he would somehow come to the conference and interrupt me during my talks.

I don't know if this happened at the time when you were there, but I used to have this joke with with Senator Blumenthal about How does this even happen?

It happened, I think, three or four times. But I'm happy that somehow I was able to play a role in convincing your family. And by the way, it brings up a great point.

The education for Lyme disease is not just the patients. It's got to be the caregivers. It's got to be the family members. Because if you're not believed and you're not supported in a healthy way, it kind of makes the healing road difficult for people.

Yeah, until that point, I felt like I was getting a lot of pressure from my family of like, when are you going to get better? And not understanding that there are some good days and there are some bad days and this isn't going to be a linear path.

And I felt like after they went to that conference, there was a greater understanding of that. And the difference for me, by the way, if I would have said that at the time, and it is true, by the way, that if I saw a thousand patients, there would be a thousand different protocols.

But now, after doing this for 40 years with 13,000 people, for me, in my world, the Dapsone protocol, Dapsone combination therapy, hitting these biofilm persister forms, pulsing it, looking for babesia, treating Bartonella with pulses, looking for mycotoxin mold illness, checking for leaky gut and food sensitivities, looking at the microbiome,

making sure they're sleeping, checking vitamin minerals.

These are all the six factors that drive inflammation with Pox Dysautonomia with low blood pressure, which happens from BART and mold and long COVID. And it's complicated now because the patients with chronic Lyme we're seeing now never, of course, just have chronic Lyme disease.

They always, at this point, are showing up with other factors. But the long COVID piece has made it difficult with Epstein-Barr reactivation. And I'm in the middle right now trying different protocols, because the DAPTRON protocol is highly effective and is getting many people into long-term remission.

My wife is six years in remission without one symptom. But the long COVID patients, I must admit, We don't have answers yet for them, and I'm still trying to work it through.

It's becoming a very I think from my standpoint, we need chronic disease centers of excellence. You know, your story of the doctor doesn't take enough time to listen for me because chronic diseases are like 86% of our health care costs.

and 70% of the deaths in this country are chronic disease, I've always stood up and said, I think the model, we need a paradigm shift, and we should have chronic disease centers of excellence.

So someone like you, you're a bright young woman, you went through college, you don't have to be a psychiatrist, by the way, to look at you and go, this woman is not crazy, she is sick.

Forget just the fevers, all right? I mean, that's a whole nother story. And that you, if you go to a few doctors, it's like, go to the chronic disease center of excellence in Connecticut, in Maine, And let them spend a couple of hours running through protocols.

We really need this at this point in time because our system is just not equipped to be dealing with people like you. And the limedocs out there, I train them and I do it.

There's only so many of us. This is why I'm now trying to go for NIH funds for randomized multi-center placebo trial. I'm in the process of working with an agency.

So maybe by the end of 2025, I will actually have funds to start a randomized trial because There's so many still questions about Lyme, even after 50 years roughly of discovering this.

You'd think we would have made more progress. We have in my world, but people like you who didn't see me years ago or others, you go from doctor to doctor looking for answers.

And I think we really need a shift in the paradigm of how we're looking at chronic illness. I think that would be fantastic. I highly support that idea.

I think that would have been really helpful for me, would be so helpful for so many patients with chronic illness. to help to get to the bottom of their symptoms and to help recognize that they do have multi-system infections, whatever those infections might be, multi-system complications, illnesses, inflammation, looking at all of those different factors and looking at the whole person and their whole history and truly helping people to get well, not just a 15-minute appointment, check off the diagnostic box, maybe get treatment, maybe not get treatment.

I think that's an excellent idea. How many years did it actually take through the treatment? Now that you've got the treatment, you finally were with a Lyme literate doctor.

How long did it take you to go through the treatments before you really started noticing it? And how bad, by the way, were the Herxheimer reactions? Because people also sometimes need to know this healing journey can be a roller coaster ride for people.

What was it like for you? It really is. And sometimes, you know, they, they talk about two steps forward, one step back with tick-borne illness. It can actually be one step forward, two steps back.

And you feel like, you know, I'm really not going to get it anywhere, but you are, you are ultimately moving forward. So I was on nine months of intravenous antibiotics as well as on the anti-malarial medication.

And when I first began all of that, the Herxheimer was. I felt worse than I had ever felt. Everything came out, you know, worse than ever. I called the doctor.

I spoke with the physician's assistant and she said, that's great news. That means everything is working. Stay the course. And I'm thinking, what? Why is that great news that I'm feeling terrible?

But I begin killing off the bugs. But I tell for people, you know, listening out there, there are also good herxes and bad herxes. And there is a difference because the good herx is, wow, I herxed and had all my symptoms come out, my fatigue, my aches and pains, my brain fog could be a couple of days, could even be weeks.

And then when the hurt stops, you move up to the next level of health. But there have been people in the past where it's a bad herx, where they herx and herx and herx, they stop the treatment and they're back to where they started.

And that means there's something usually interfering, right, with people getting better, that there's other inflammatory factors or downstream effects from the inflammation that's interfering with the healing process.

Fortunately for you, yes, I mean, ultimately you had good herxes and ultimately the load of the bugs got better and you did improve. And it took probably about a year to really see improvement to be declared in remission.

And my life was not back to what it had been, but it was so much better than what it was when I was totally bedridden. And I went off of treatment entirely and dove back into life too quickly.

I sort of had this mentality of like, great, I've been sick for years now. I'm done. I'm finally getting back to life. All I could talk about was that word back.

I can't wait to get back to life. I can't wait to get back on track. I can't wait to get back to work. And so I dove in. I moved to Vermont. I was trying to get back to that skiing lifestyle and I started working and I relapsed completely within three months because I had no defenses in my body.

I was on no medication. I dove in way too fast, put my body under way too much stress and was all the way back to point zero. And just a point about that I've had patients on 12 months of ivory rocephan not through me but through other doctors who relapse within a month off the treatment and then I gave them a persister biofilm protocol like that some combination therapy and they stayed in long-term remission and at the time when you're being treated by the way We did not know about biofilms and persisters.

No one knew about it. So it's not that it was the dark ages, but you were being treated with the best treatments that all of us had at the time. But it wasn't until, I think, it was about 10 years ago, 11 years ago, when John Hopkins researchers and Eva Schoppe from the University of New Haven in Stanford Kim Lewis, they all started then talking about biofilms and persisters.

That's when the light bulb went off in my head because I had similar patients to you that went to doctors for a year on rocephanin relapse. And by the way, when I check people's adrenals, we always do their adrenal function and hormones.

I tell people not to do what you did, which is go slow when you start going back into life because if adrenals aren't up to speed, it's like the battery of your body, right?

With the adrenals apart from thyroid and everything. You don't have the bandwidth, right, to be able to do that. And

I have people feel so good on the treatments.

They rush out and play tennis for six hours and they're in bed for three days after that because they just overdid it. Yes, that's exactly right. Yeah, I didn't know the term post exertional malaise then, you know, that's now part of the lexicon because of long covid.

We didn't have the same treatments then, you know, just as you were saying, I was on IV rosephin because that was considered the best at the time. And I did lose my gallbladder as a result of it.

Advice for doctors and closing remarks

We knew that that was a risk at the time, you know, and then just so treatments are different now, you know, as you said, we did the best with what we had at the time.

Yeah. No, so this is a great, by the way, this is a great story. And I want to remind everyone, for people who have not read this, you really need to read One Tick, Stop the Clock, because Jennifer is very eloquent in this book explaining it.

And I think for people out there who've suffered and have gone through it, it's always good to hear from someone else like, hey, I wasn't the only one.

This is exactly my story. Your story is really many people's stories who are out there with this. So just the final word of advice. You've been through all this.

You're obviously much better. What words of advice would you give to the doctors you've seen before, to the health care system, to friends, family? What would you say after everything you've been through?

What do you think needs to change at this point in the system so that people like you are believed? So I mean so much. First of all, I think the most important thing for doctors is listen to your patient.

You know, listen to your patient and they'll tell you what's wrong with them. So, you know, really take into account the patient narrative. And I know that the insurance companies make that nearly impossible with 15 minute, you know.

Appointments, you know, but but figuring out a way you know to to get a patient's full history. What I recommend to patients actually is to write out their history and write a synopsis of it in one to two pages to bring into the doctor and sometimes give to the doctor beforehand that they can read.

So that, you know, you're saving some time. It's all, you know, it's all written out there. So that's one piece of advice I have. And, you know, for others out there, just to believe these patients, you know, even if someone doesn't yet have a diagnosis, it doesn't mean that they're not sick.

It means that doctors haven't yet figured out what's wrong with them, but no one knows their own body better than that person. no one knows your body better than you do and so you know for patients just you know continuing to be your advocate to speak up for yourself to say no something is wrong here i know something's wrong i know you know and pushing on to the next doctor you know until you get an answer because you deserve that and you deserve to be well.

Yeah, you know, I think the validation has become a little bit easier in this day and age, mostly from long COVID, because a lot of people weren't believed with long COVID in the beginning.

And then, you know, all of it. Now you can get disability payments for it. It has been believed. And, you know, the American Academy of Sciences are talking, you know, infection associated chronic illness.

I don't particularly like the term because, and the reason I love chronic Lyme, which most people say it's in

outdated, but it is a chronic infection.

Sorry, folks, it is. And I like Lyme-EMCIDS because by saying EMCIDS for me, multiple systemic infectious disease syndrome, it tells people there are 16 factors.

that you need to look at. So at least you have a map to go on a journey for someone like you, who is sick. And you're not just like, where do I look? It's like the MSIDS model gives you hope to know that is the road that you need to be on to find answers.

But I think it's gotten a little bit easier. But I will tell you, I'm reaching out at this point for people to do randomized trials. And it's interesting, some of the responses I'm getting even back from research is still like, well, we have so many questions about this.

And it's like, you're not really in my world. It's like, I don't actually really have that many questions. The biggest questions I have is, what is the best treatment for long COVID?

Because it's one of those nails in the foot that is interfering with some of my patients getting better from Dapsone combination therapy, and some have gotten better with disulfiram, the other persister drug that Dr.

Liegner has published on. Jen, I want to thank you so much. For taking the time to write your story, get it out there for people. I've written books and I know what it is to write a book.

It is not an easy process and you know this yourself after being through it. So thank you for taking the time today again for everyone. The name of the book is One Tick Stop the Clock by Jennifer Kristol.

Jen, thank you again for today. I think people are gonna get a lot out of our discussion today. My name is Dr. Richard Horowitz. I'm co-host of the Healing Lime Summit 2.0 with Dr.

Talks. We look forward to seeing you again soon. Thank you for joining us. Thank you. Thank you for tuning into Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

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